“It Was Kind of Scary”: The Experiences of Children and Young People with an Intellectual Disability of Undergoing Clinical Procedures in Healthcare Settings

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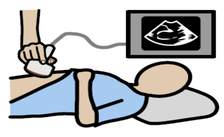
Background

- Clinical procedures are activities performed by healthcare practitioners for the purpose of diagnosing, monitoring and/or treating an illness such as blood pressure testing and scans.
- Children and young people with an intellectual disability frequently visit healthcare settings; however, there is currently little empirical evidence to determine how these individuals and their parents experience clinical procedures (Oulton et al., 2015; Peninsula Cerebra Research Unit, 2016).



Research Question

- How do children and young people with a mild to moderate intellectual disability and their parents experience non-urgent clinical procedures?

Methodology and Methods

- This ongoing study has utilised a qualitative research design underpinned by the principles of Classical Grounded Theory (Glaser and Strauss, 1967; Glaser, 1978).
- To date, 26 semi-structured interviews have been conducted with a convenience sample of 11 children and young people who have a mild to moderate learning disability and are between the ages of 6-15 and their parents (n=15).
- Communication in some interviews with children and young people has been aided by the use of the tool known as “Talking Mats”™ (Murphy, 1998) which is essentially an A1 sized surface on which a person arranges symbol cards in response to questions.
- Completing a Talking Mat increased the amount of information conveyed by children and young people.

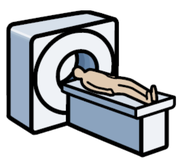
Results

Preliminary analysis of data shows that:

Children, young people and parents often feel worried and upset before and during clinical procedures

“Sometimes I’m a bit agitated because, although I’ve had a number of blood tests before, I’m not sure if something is like going to be a bit dangerous or something like that.”

John *— Aged 15*



“[Ben] had to have an MRI [scan]... I got the head end, my sister got the feet end... and I just cried all the way through it.”

Jenny *— Parent*

Children and young people report that they dislike being physically held still for procedures and that they prefer to be told about what will happen beforehand

“Remember when you pinned me down...? I hated it when you did that.”

Ben *— Aged 11*

“It was kind of scary and you don’t want it to happen, so you like try and move.”

Tabatha *— Aged 12*

“**Interviewer:** And you didn’t like arriving at the hospital either?
Neville: No.
Interviewer: No. Can you tell me a bit more about that?
Neville: Because Mum wouldn’t tell me what I was doing.”

Neville *— Aged 11*

Parents report that other factors contribute to the worry and upset that they and/or their child experience during a procedure

“Professionals find it very difficult… to talk to [John] as simply as possible. Sometimes I struggle to understand them as well in respect of the language they use.”

Rachel *— Parent*

“Regularly now we would wait for three hours… The whole procedure would on average take at least two hours in general, or if not three, by which time [Edward] is beside himself and will not cooperate at all.”

Emma *— Parent*

Conclusions

- Clinical procedures are challenging events for children and young people with intellectual disabilities and their parents.
- Practitioners should aim to make reasonable adjustments that respond to the concerns of children and young people with intellectual disabilities and their parents such as attempting to book early appointment times to minimise waiting periods.
- Children and young people with intellectual disabilities can and should be consulted about their healthcare whenever possible.

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